

Renal Transplantation for a child with ASD

A positive experience for all

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Matron

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Evelina London



Guy's and St Thomas'
NHS Foundation Trust

Background

- 9 years old
- Antenatal diagnosis of Bilateral Renal Cystic Dysplasia associated with reflux grade 1V
- Middle child of 3
- Diagnosed as being on the Autistic Spectrum aged 4
- PEG feed dependent
- Difficult behaviour and sleep patterns
- Monitored via Chronic Kidney Disease Clinic
- Deteriorating renal function from late 2014

Inpatient History

- Several admissions
- Circumcision
- Bilateral orchidopexies
- Insertion of PEG and adjustments
- Usually accompanied by Dad
- Usually fraught for Felix, found the ward noise disturbing and uncooperative with observations and interventions.

Psychological support

- Attends small supportive school
- Has a resident Nanny, whom he has bonded with very well
- Behavioural therapist at school
- Commenced music therapy provided by Evelina London
- Both Nanny and behavioural therapist start accompanying him to out patient appointments

Transplant Preparation

- January 2016, Dad identified as best match
- Transplant date set for August
- Play specialist commences transplant prep
- Music therapy continues
- Referral to Clinical Nurse Specialist for children with Neuro- disability
- Monthly MDT meetings including anaesthetist, surgeon and ward staff
- Personal plan devised, refined and agreed with parents, carers and staff

Considerations

- Pre op preparation, any difficulties identified
- Admission – timing, bed space, who would be there
- Cannulation
- How to get him to theatre
- Mode of induction
- Post op in recovery- who should be there
- To ward or PICU
- Nursing staff
- Medication
- Unexpected events
- Discharge and follow up

Transplant

- Staff identified to look after him, pre and post transplant
- Pre op checks go without hitch
- Transplant carried out
- Returns to the ward
- within the first 24hr post up, diminished urine output, reduced perfusion on scan
- Back to theatre, PICU electively post up overnight
- Graft functioning
- Psychological support continues
- Discharged day 11

Since Transplantation

- Taking oral fluid and diet
- PEG still required but not totally dependent
- Has been admitted a few times, able to be in main ward, not distressed, confident with the staff
- Parents delighted with progress, very positive feedback from experience